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Sharing Health-Related Data and Buddhism

Malcolm Voyce*
[1]Macquarie University, Australia

ABSTRACT

Health-related research funders, regulators and journals increasingly expect de-identified health research data to be shared widely. This article examines non-western reasons for decision-making in Thailand, a Buddhist country, to explore the extent to which Buddhist DACs should make decisions based on Buddhist norms. The method used in this study is a qualitative method with literature and sociology approaches. Meanwhile, the source of data came from the DAC and the perceptions of various Buddhists. The results of this study suggest that the social impact of big data on health has the support of Buddhists and the community so that there is data transparency that can be known by the wider community. In addition, health data is big data that can utilize technology in its management. In conclusion, data sharing raises concerns about the accuracy and reliability of data so that it needs supervision so that the data presented is the correct data.

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Introduction

With the development of computer technology, it is possible to assemble large-scale data (Brunton & Nissenbaum, 2015; Holmes, 2017; Schneier, 2015). These may consist of electronic health records or data collected from routine clinical care, clinical research conducted by clinical research teams or contract research organizations. Health-related research funders, regulators and journals increasingly expect that this data will be shared beyond original research teams (Admin, 2017; European Medicines Agency, 2014). Big data is a term that refers to the binding of advanced predictive tools with large data sets. This data may be deployed with the aim of tracking, monitoring, analyzing, and disseminating this information (Boyd & Crawford, 2012). The defining feature of big data is not its size alone but its capacity

*Corresponding author: author email address: malcolm.voyce@gmail.com
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to search and integrate large data sets to predict future events, activities, and behaviors (Boyd & Crawford, 2012).

Big data may be compiled in various ways. *First* is based on organizational records, which include economic transactions, contracts, company registrations or governmental institutions such as births, deaths, and marriages. *Second*, is accumulated from the internet and includes e-commerce activity, exchanges on social media platforms, and the use of browser searches. This type of information can include pictures, videos, meta-data and text comments on various apps and sites (Qualman, 2012). *Third*, big data source relates to people's physical movement and is collected through private and public surveillance cameras, smartphones, and satellites. Facial (and other) recognition technology may be used to track individual movements. Indeed, the growing number of sensors embedded in objects, and bodies, and places intensifies the potential for surveillance of individuals (Miraz, Ali, Excell, & Picking, 2015). While there are forms of data that are not health-related it is important to note them here as these may be combined with health data to form the final large data set.

Various rationales for sharing heath data include: *First,* maximizing the utility of the data sets, in that data sets may have a secondary usage by other researchers. It is argued this will reduce redundancy and facilitate further innovation. *Second,* improving rigor and transparency of the health outcomes. Data sharing would encourage researchers to produce high quality work with appropriate data management, storage, and archiving. It is now accepted that organizations should have in place data-sharing policies with the appropriate governance mechanism (Waithira, Mutinda, & Cheah, 2019). Instead of having data completely open access, data requests are often channeled through a DAC, a formal or informal group of individuals responsible for reviewing and assessing data access requests (Cheah & Piasecki, 2020).

This article takes as a starting point several strands of scholarship as regards big data. Firstly, recent studies have shown how big data is embedded in the age of 'surveillance capitalism' (Iliadis & Russo, 2016; Ruckenstein & Schüll, 2017). In this regard Zuboff in *The Age of Surveillance Capitalism* has described the free collection of big data as a form of 'surveillance capitalism' (Zuboff, 2019). She argues that this form of capitalism is "a new economic order that claims human experience as free raw material for…hidden commercial practices of extraction" (Zuboff, 2019). The economic value of this "behavioral surplus" is then further enhanced when combined with "machine intelligence," such as algorithms, which generate predictive modeling of human activities (Zuboff, 2019). Hence the need for this research.

Method

This research uses qualitative methods with two theoretical approaches one by the literature on 'surveillance capitalism', and another by a sociological critique of 'medicalization'. The data sources obtained were from Data Access Committees (DACs) and Buddhist perceptions of data sharing. The data collection techniques used were observation and literature review. The data analysis techniques used were data reduction, research data display and conclusion drawing.

Result And Discussion

The Social Impact of Big Data on Health: Some Theoretical Approaches

The two concerns revealed by this analysis are that this 'extraction' will benefit the rich and cause inequalities of wealth. Moreover, that many companies take consumers private information and without their permission sell it to other companies. There is also the concern that such data's accidental or deliberate release will cause embarrassment, paranoia, or mental illness (Price & Cohen, 2019). Lastly, there is the question of how research has been funded and the misrepresentation of evidence in pharmaceutical research (Goldacre, 2014). Secondly, we use the concept of *medicalisatio*n to explain how medical knowledge has been applied to behaviours that are not self-evidently medical or biological. Medicalisation has been seen as a form of social control in which medical authority has expanded into domains of everyday existence. Medicalization is not a simple, one-sided process of medical domination, but rather a multi-directional process involving different parties, including consumers, patients, doctors, drug companies and, frequently activists (Quirke & Gaudillière, 2008).

In practice the process of medicalization strips subjects of their prevailing social context, so they come to be understood in terms of a biomedical ideology, resulting in a disregard for overarching social causes such as unequal distribution of power and resources (Singh & Singh, 2005). These explanatory modes of medicine have paved the way for developing and integrating pharmaceutical therapeutics and diagnostic tools into biomedical practices. Thus, the art of medicine has been transformed into a technocratic institution where technology and medicine were one and the same, and the standard of care became defined by efficiency, accuracy, and perfection.

Despite the tremendous value of advanced technologies, the technocratic model indirectly espouses a profit-driven business model and rewards aggressive intervention which is often at times at odds with the desires of the patient (Davis-Floyd, 2001). In short, technological advancements have served as the stepping stool in biomedicine's quest for excellence. Furthermore, the biomedical technocracy has distanced itself from the average person by formulating terminology and medical jargon that alienates the patient from the healing process. Then, there is the debate about the position of traditional Thai medicine (Senachai, 2019) in its relationship to biomedicine (Wieringa, Engebretsen, Heggen, & Greenhalgh, 2017). We make this analysis as the DAC might consider the religious and cultural underpinnings of traditional forms of medicine and how these views might be respected in light of the arguments in favor of data sharing.

In analysing these forms of Thai medicine we note that 'Buddhist medicine' is a convenient term commonly used to refer to the many diverse ideas and practices concerning illness and healing that have emerged in Buddhist contexts. Buddhist medicine has never been a cohesive or fixed system. Instead, it should be thought of as a dynamic, living tradition with a few core features and much local variation (Salguero, 2018). We assume that Thai traditional medicine incorporates ideas form Buddhist medicine, however conceived. Secondly, that biomedicine has the predominant cultural position in Thai society (Kirsch, 1977). It is acknowledged that

Thai medical practitioners deploy methods from western medicine such as ultrasound, x-rays, and blood tests. Furthermore, that Thai medical practitioners often incorporate some folk elements of traditional beliefs that may be considered by western medicine as on the margin of credibility. As in many countries there is in existence 'medical pluralism' where treatment may involve forms of syncretism, where in any one community patients and their helpers may resort to different kinds of therapeutics, even if these explain the disorder in mutually incompatible ways (Amzat, Razum, Amzat, & Razum, 2014).

Violette Lindbeck (Lindbeck, 1984) has argued that one of the major ethical problems in Thai traditional medicine has been the intrusion of Western medical models into this tradition. She argues that American agencies, eager to bring modern medicine to Thailand, delivered financial assistance and the whole package of American medical education, technology, and health care delivery patterns. One result has been 'over medicalization', since Thai doctors can charge only for actual treatments and drugs by tradition. Moreover she argues medical students have become lured by the prestige of science and high incomes (Lindbeck, 1984). Samuel has suggested that the major medical traditions of Asia, such as *āyurveda* and traditional Chinese medicine as well as traditional Tibetan medicine, for all their differences from biomedicine have some compatibility with western biomedical understandings (Samuel, 2006). However, there are elements which marginalize or disrupt this compatibility. Here reference may be made to divinatory procedures, spirit attack or flows of subtle 'energies' which are not assimilated to the biomedical model.

We therefore consider that the DAC may be inclined to give respect to the values underlying Thai traditional medicine and its links with Buddhism and therefore be cautious about the claims of biomedicine as enshrined in health data. We note three aspects of Thai medical approaches. Firstly, Dhamma is seen as a form of medicine. In the sutras, we find analogies that describe the Buddha as a doctor, knowledge of Dhamma as the treatment, and all lay people as patients. The occurrence of disease is closely related to one's mental, physical and spiritual health, society, culture, and environment. It is not enough to approach medicine in a manner that simply eradicates symptoms; the psychosocial aspects of disease and its mind-based causes and remedies must be a primary consideration. Holistic care involves the harmonization of all these elements, and Buddhist philosophy offers great insight for the physician. The Buddhist medical literature lays out moral guidelines and ethics for a health-care practitioner and this has corollaries in the principles of medical ethics: nonmaleficence, benevolence, justice, and autonomy. There is emphasis on loving-kindness, compassion, empathy, and equanimity as key attributes of an ideal physician (Zysk, 1998). Secondly, there is the widespread belief in spiritual practices, ghosts and natural products and shamanistic forms of healing to benefit health and lifestyle (Selin, 2013). Thirdly, as we have indicated, there is still some strong belief in Thai traditional medicine (Senachai, 2019).

According the DAC they may be skeptical about the idea of data sharing to the extent that it promotes a western form of biomedicine. This approach may be because science increasingly dominates the values and assumptions of biomedicine. There is a disjuncture between the biomedical model and the beliefs of Thais about medicine that ignore traditional Thai medicine (de Souza, 2012). The consequences

of these arguments are that medical science resting on the scientific method and as constructed by the medicalization critique and the above critique of biomedicine, renders many indigenous knowledge systems as invalid, illegitimate and irrelevant' (Ngara, 2017). In addition, our third argument is the Values of Privacy and Autonomy. It is often argued that of big data compilations such as electronic health records, should be an anonymous form. However, big data is regularly compromised even if data is collected anonymously. We may well therefore ask what the importance of preserving privacy is.

Privacy scholars have demonstrated how the meaning of privacy has evolved since the eighteenth century. Initially, privacy was understood in terms of freedom from (physical) intrusion. In later times, it became associated with freedom from interference into one's personal affairs, including one's ability to make decisions freely. We summarize two basic kinds of privacy that we conceive as important regarding data sharing and Buddhist practitioners. Firstly, *decisional privacy* may be seen as the freedom from interference from others regarding one's personal choices plans and decisions. Thirdly, *informational privacy* may be seen as the ability to control information we consider personal (Tavani, 2003). We assume above that such an idea of privacy incorporates the idea of *autonomy* and the possibility of self- determination embodied in an individual 'whose actions are governed by principles that are his own' and who 'subjects his principles to critical review, rather than taking them over unexamined from his social environment' (Benn, Pennock, & Chapman, 1971).

Then many writers have argued that the concept of privacy and autonomy are western concepts that signify individualism, liberalism, the public-private divide and the rule of law (Bennett & Bennett, 1993). Several writers have argued these concepts are not present in Thailand, for the following reasons. Firstly, in Thai society, traditionally family members share the same household. In this space, there is no space for individualistic privacy. Secondly, the nature of society is perceived as an 'affiliation society' where members depend on security and patronage in a hierarchical form of vertical structure (Kitiyadisai, 2005). Thirdly, the collection of personal information has been a long-standing practice in Thailand, as the state subjects its population to bureaucratic surveillance through its citizens ID cards, households' registration passbooks, social welfare cards and so on. At the same time, government departments widely share information on subjects. The concept of privacy has in general been limited on the basis of collective public good and national security (Ramasoota & Panichpapiboon, 2014).

However, for younger generations, changes are taking place in this cultural space, as privacy is becoming a concern amongst the urban educated middle classes (Nyblade, O'Mahony, & Sinpeng, 2015). Pirongrong and Panichpapiboon have shown that the upper economic strata are apprehensive about losing privacy rights and collecting personal data. With the passing of the *General Data Protection Regulation* in the European Community Thai companies should they wish to deal with the EU, may become more stringent in respecting privacy. We see this EU legislation as having a flow-on effect as regards increasing respect for privacy in Thailand in general. The uneducated rural people are indifferent to such issues. While Buddhist teachings propound that while the self does not exist, it is conceded that it does have a conventional existence on the basis that dignity is needed for the

individual to develop their inner capacities. The fact that Buddhism rejects the individual self does not necessarily mean it rejects ideas of privacy, autonomy, or human rights. In order to understand this 'counterintuitive argument' Hongladarom distinguish between the absolute and conventional level of this dichotomy (Capurro, 2008). From an absolute point of view there is no distinction between subject and object. If there is no inherently existing self then privacy is grounded on the conventional idea that it is necessary for democracy, which means that privacy has an instrumental instead of an intrinsic, or core value. The distinction between intrinsic and instrumental values has an insecure foundation as all values rest on our attachment to them. The conventional self exists only as a convention and is in reality a mere illusion in terms of the 'ultimate truth.'

We perceive the recognition of the conventional self is important in the human need for special recognition and support for the development of their spiritual capacities. It follows that Buddhism supports the notion of autonomy not as an achievement for its own sake. Rather autonomy may be seen to have an 'extrinsic value'. Morgan notes that there are two reasons for this. Firstly, that autonomy is necessary to assist in the progress to Nirvana, not necessarily, because there is something good in itself about being autonomous. Secondly, the point of the path to Nirvana is to transcend conventional truth. Conventional truth is vital to proceed toward Nirvana, but it is not of intrinsic value in itself. In this context, it is acknowledged that individuals need a caring environment to develop fully into mature individuals. Once a person has obtained Enlightenment there is no value in autonomy as autonomy is of temporary extrinsic value only (Morgan, 2013). We conclude therefore that autonomy should be respected. The importance of autonomy, given the Buddhist view of the self, is the idea that practitioners may learn from their mistakes and accordingly assess their options. It follows that this capacity might be reduced by data sharing was undertaken as data sharing as such sharing may lead to a breach of privacy.

Buddhist View on Data Division

The final argument against data sharing concerns that scientific data may not be sympathetic regarding Buddhist ideas of personal development and its inherent epistemology. We argue that big data may impact the subjectivity of Buddhist practitioners through their over-reliance on scientific data, which we suggest has influenced the views of medical practitioners and their patients. In order to develop this argument we consider that the DAC would take into account the Buddhist ideas on the different forms of knowledge, that do not necessarily regard the 'mind' (Coseru, 2009) (as implicit within the biomedical model) to constitute the primary means of knowledge (Moore & Robinson, 2016). This argument implies that biomedical data might be evaluated according to a different world view, bringing it into conflict with some of the values of Thai traditional medicine. In order to explore these matter we inquire 'as to how Buddhists interpret human experience?' This is an appropriate question to ask in order to indicate how data sharing may impact on personal development.

We will indicate how Buddhist texts have described the means by which the various sources of knowledge might be evaluated. For the sake of our argumen we

suppose that western biomedicine is in Buddhist terms a source of 'knowledge'. Although we concede it in strict Buddhist terms it may not have the same status as knowledge derived from Buddhist texts or a Buddhist community. We may ask whether this process of knowledge evaluation might be subverted by data sharing as with the linking of personal information in large data sets, this may result in privacy and consequent autonomy being stifled? In order to develop the above argument we explain more fully the nature of Buddhist epistemology. The Buddha taught an approach to knowledge that had less to do with the application of reason but more on how insight could be obtained through knowing oneself (Coseru, 2009). Buddha warned not to be misled by purported avenues of knowledge such as oral tradition, logic or reasoning and the apparent authority of a person.

Two aspects of this approach are important. On the one hand, the Buddha warned that ultimately each individual must make up his own mind independently on religious matters and disregard textual knowledge or authority as a means to maintain autonomy and stimulate personal development (Ekman, Davidson, Ricard, & Alan Wallace, 2005). At the same time Buddha also argued that meditation as a form of knowledge-development or personal form of epistemology, creates the opportunity to understand the nature of the self and the fleeting nature of the mind and the Law of Dependent Origination. We argue that data sharing and the possibility of the release of personal details creates a body of information that may be detrimental to Buddhist practitioners. We argue this in two moves.

Firstly, we note the claim advanced by social theorists that within big data sets the individual person is being reduced to a collection of information that might be stored and manipulated like any other data and that this process affects subjectivity (Hongladarom, 2009). Here we refer to the various formulations of sociological theory as regards the idea of 'fragmented selves' and the approach of Deleuze and his concept of the 'dividual'. We suggest that Deleuze's idea is instructive as it indicates how an individual may be divided into discrete 'masses, samples, data, markets, or "banks"'; it is in fact endlessly divisible. We contend that this form of argument about the shape of fragmented selves may concern the DAC as such a line of thought indicates people have fractured selves and consequently may not have the calm minds necessary for meditative experience (Charoensukmongkol, 2014). This form of argument could be developed by the DAC to formulate that reliance on biomedical data due to data sharing may be unhelpful.

Secondly, we note the argument that computer driven technology (and by extension we argue social media and scientific research) has been described by Buddhists as a kind of 'life-style-factor' that is unskillful in that it creates an *asrava*, a leaking away of attention energy that is seen as a wasteful and mentality polluting activity (Hershock, 2006). We give these ideas of fragmented selves and the decentering forces of computer-driven research a local bearing with the Thai concepts of the person. As Stonington has shown in his field work dealing with end-of life-care patients that he found he was not treating 'bonded and consistent individuals' but people who saw themselves as a product of a broad array of processes such as the product of karma, gifts given and received and magical knowledge (Stonington, 2020). Such individuals may recognize themselves as 'multi-authored entities' or as 'distributed, partible, fluid, transient persons' (Mosko, 2010). We conclude that data sharing and the reliance on

biomedical-generated data may distort Buddhist practitioners from their traditional ways of evaluating different forms of knowledge and the fluid nature of the self in order to be able to recognize the empty nature of personhood so necessary for spiritual development.

There are several cases of data sharing, including: Firstly, the DAC would be inclined to want to follow the example of Buddhist kings and share generously (Harvey, 2000). In this regard the modern Thai monarch has established a position in society where the king is regarded as a source of great charity and benevolence. Successive Thai kings have embodied the Buddhist concept of kingship with the ideal of selfless giving through nationwide endeavors such as public health care (Seo, 2016). In this role kings have attempted to reflect the moral virtues found in the Vessantra Jataka as indicative of the highest form of merit-making (Jory, 2002). In recent times, the festival pertaining to the celebration around this Jataka has been dismissed as not reflecting true Buddhism. Nevertheless, the use of merit-making by the Thai monarchy and government to solidify their position and create unity in society has continued until at least the late twentieth century (Jory, 2016). The DAC might well recall the Jatakas and the tradition of generous king and how these texts created a moral form of creativity that the Committee would want to emulate (Hallisey, 2010). This impulse would coincide with the idea of Buddhism as a healing therapy and ideas of social engagement. Secondly, data sharing is an expression of Buddhist compassion and the recognition that an individual's best form of development is through the cultivation of compassion. This quality is usually associated with the *bodhisattva* who cultivates a moral orientation that centrally involves cultivating oneself in order to be the kind of person who can reliably, effectively, and wisely benefit others to assist other sentient beings to enlightenment in preference to their own needs.

These comments reflect the fact that the Buddhist tradition has a strong emphasis of compassion and giving. One of the necessary attributes to development is the cultivation of *dana* or generosity, along with *metta* (loving kindness) and *karuna* (compassion). Loving-kindness may be seen as 'devotion to the aspect of [others] welfare, and their claims'. Similarly, compassion is concerned with 'relieving the suffering of others and has the function of not letting others endure suffering'. Acts of giving are evaluated according to three factors. These include the quality of the donor's motive, the recipient's spiritual purity, and the gift's kind and size. As in all other aspects of Buddhist practice, the intention-action nexus is crucial when evaluating an action's consequences and worth (Simpson, 2004). One special category of gift called *dana* is a category that deals with gifts given for the sake of giving and not for the sake of gaining merit oneself. This is the case as any gift given with an expectation of reward loses its capacity to attract good *karma*, as such a gift belongs to the ordinary social world and is regarded as no different from any other form of commercial transaction. We consider that someone who adopts this form of altruism would be cultivating compassion and altruism. In this way, the DAC would sympathize with the acts of people who gave their data to obtain merit and consequent good to develop conducive minds ready for Enlightenment.

Conclusions

We have noted the concerns about the accuracy and reliability of data that may result in research obtained through data sharing (Ozair, Jamshed, Sharma, & Aggarwal, 2015). The almost inevitable breaches of privacy may occur through a lack of confidentiality or as a result of security breaches (Pukawan, 2006). Therefore, we argue that the DAC would take widespread concerns about possible security breaches seriously. We suggest this is a valid concern given that the western ideas of individualism are growing in Thailand and that young people need personal autonomy to develop their individuality. At the same time, some members of the DAC may feel uncomfortable with that fact that data may be mined for the benefit of corporations. A less convincing argument against data sharing is that such sharing may distract Buddhists from the holistic view of medicine as presented through traditional Thai medicine. However, in light of the idea that giving creates good karma through the development of compassion, we consider that this argument encourages the DAC to favor sharing data.

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